

fundraising news

National MPS Society Receives Four-Star Charity Rating

The National MPS Society is pleased to announce it has received the prestigious four-star Charity Navigator rating. This “exceptional” designation from Charity Navigator differentiates the National MPS Society from its peers and demonstrates to the public it is worthy of their trust. Receiving four out of a possible four stars signifies that the Society adheres to good governance and other best practices that minimize the chance of unethical activities and consistently executes its mission in a fiscally responsible way. Only approximately one quarter of the charities evaluated have received the highest rating, indicating that the National MPS Society outperforms most other charities in America.



Joseph and Paige Migliozi wanted to do something special to honor the memory of their son, Christopher, who passed away from MPS I. Christopher’s 12th birthday would have been April 24, so Joseph decided to participate in the Westfields Sprint Triathlon on April 26. The event is a 250-meter swim, 12-mile bike ride and 5k run. Their first fundraiser, the Migliozi’s solicited small donations from friends and family.

“From a fathers perspective, I could never put into words what I went through watching my son get sick and then pass away,” said Joseph. “The hopelessness and powerless feeling knowing there was nothing I could do to make him better. Being a father of a child who has passed is a lonely group to be in. This small fundraising event is one thing I can do in his memory. I know he is watching over me and rooting me on when my knees are yelling and back is throbbing. ‘Go Daddy, you can do it!’”



Christopher Migliozi (MPS I)

FUNDRAISING REMINDERS

- Don’t forget to submit a brief article for *Courage* about your fundraising success stories and suggestions—they are terrific resources for other families planning events.
- Check out the fundraising section on the website for more information or to post your event.
- For free MPS Society brochures and donor envelopes, or to submit information for the website or *Courage*, send an e-mail to Terri Klein at terri@mpssociety.org.

Keep in mind—the Annual 5K Walk/Run and the Annual Fund are great ways to raise money for the National MPS Society.



Karsyn Wallace (MPS III)

The Wallace family put their efforts into multiple fundraisers this year. Their community has rallied for Karsyn (MPS III) by supporting a Purple Lemonade Stand for Sanfilippo Research, a Norwex party and a Thirty-One Party.

Text to Give Is So Easy!

We had a great fundraiser for MPS at my company. It was almost without any special advance planning and no complicated setup because we did it at an existing event. This will work anywhere an audience is seated who are inclined to help. In our case, we were having an annual company meeting with at least 400 people. We included a talk by an A-list MPS advocate, Mark Dant. He told a wonderful and compelling story about his family's experiences. At another event, some of these folks had seen Steve Holland share an inspiring story about his family's journey. Some of my colleagues approached me and said, "Everyone wants to know how they can help. Next time we do this, let's get folks to donate to the cause."

At our next sales meeting, we had a large 400 person audience. The guest speaker spoke about MPS. The following day during our continued meeting I went on stage and told the audience about the National MPS Society's Text to Give app. We projected an image of the live Text to Give website at that moment, which includes a thermometer with donations received, who donated and a total. I told them to text the word COURAGE to 41444 and the rest will happen automatically. Right away, attendees began texting donations. It takes just a few seconds on your smart phone! The next morning when the audience reconvened, I told them we needed more participation and projected the thermometer showing progress. I reminded them of the applause that rang out when I mentioned we could all give. But the applause had been louder than the number of givers so far.

Within 15 minutes, the amount went up several thousand more dollars. It was exciting for the crowd to watch the progress. It was motivating to see all the names of those donating scroll onto the screen too.

By the time we were done, we had given almost \$10,000. My company then gave a matching grant. All this was done with very little preparation, just a few phone calls with Terri Klein, development director at the Society. It is very easy and no money handling on our part was necessary.

Steve Smith, member, National MPS Society



Million Dollar Bike Ride

Team MPS, which included the National MPS Society and the Ryan Foundation, raised \$50,000 at the Million Dollar Bike Ride hosted by the University of Pennsylvania. This amount was matched by Penn and a grant will be issued for MPS research in the amount of \$100,000! What an incredible effort in this partnership. Thanks to everyone who attended, donated their time, and/or made a donation and raised awareness.

Our riders included the Brockman Team, Dant Team, Degand Team, Hall Team, Miller Team, Van Handorf Team and many more!

Durable Goods—An Endowment Gift

Some people like to give a gift that is continuous and lasting. They get a great satisfaction committing to something that continues over an extended period rather than a one-time occurrence. These types of people like to give gifts of memberships in clubs that send out their wares regularly, such as books, coffee, flowers, etc. Each time another gift is delivered the giver's original sentiment is renewed and endures.

A very similar "good" occurs when someone makes a commitment to the National MPS Society. They create an endowment so that, every year, a certain amount is transferred to the fulfillment of the mission. It can be for a specific purpose or for general expenses, but consistency is the desired result. Because only part of the annual earning is involved in this transfer, the principal of the endowment fund continues to support the gift in perpetuity.

If creating a gift for a loved one that will be enjoyed throughout the entire year sounds good, just imagine creating a gift that continues beyond your lifetime. It may be set up as a final gift from your estate, or one that is built up over the years by a series of gifts. An endowment becomes a lasting reminder that the Society's mission is worthy of such durable support.

Endowment funds may be named to honor an individual or family. The annual payout may be directed toward the Society's many programs and can be funded with gifts of cash, real estate, life insurance policy beneficiaries or other assets.

Creating the endowment is not complicated and it can make an incredible difference for the Society. Return the insert card below to the National MPS Society, and inform us if you have left a gift in your will and if you would like more information about being part of the Rising Sun Legacy Circle. Contact Terri Klein, development director, at terri@mpssociety.org or call 919.806.0101 if you would like more information about estate planning, bequests or endowments. You may also visit our website at www.mpssociety.org and search Planned Giving.

Consider leaving a legacy. Please remember the **National MPS Society** in your will. To leave a gift, simply share this sentence with your attorney or financial planner:

"I bequeath \$ _____ or _____% of my estate to the National MPS Society, P.O. 14686, Durham NC 27709." (FEIN 11-2734849)

- I have included the National MPS Society in my will
- I would like more information about the Rising Sun Legacy Circle
(Individuals who have recognized the Society with a legacy gift)
- I would like more information about gift planning, bequests and endowments for the Society.

Name

Address/City/State/Zip

email

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WAYS TO GIVE AND INSPIRE HOPE IN 2015

Fundraising Committee:

Jeff Bardsley
Alison Blue
Stephanie Bozarth
Brooke Carter
Steve Holland, *chair*
Larry Kirch
Terri Klein
Amy Miller
Amber Mongan
Lisa Muller
Aaron Thompson
Holly Thompson
Lisa Todd
Laurie Turner
Barbara Wedehase

- Gifts in honor or in memory of a special person.
- Matching gifts through your employer (check with your human resource office).
 1. Request a matching gift form from your employer.
 2. Complete the employee section of the form.
 3. Mail to the Society and we will process the gift!
- Courage Pages—Share your family story with your own web page to raise awareness and funds.
- Contribute through the Combined Federal Campaign if you are employed by the federal government—CFC #10943.
- Designate the Society as a member of your local United Way. You will need to supply them with the Society's name, address and Federal ID number (FEIN #11-2734849).
- Give to the Annual Fund.
- Major gift (usually 10 times that of your Annual Fund gift).
- Planned gift (visit our website and search Planned Giving).
 1. wills or bequests
 2. charitable remainder trust or charitable gift annuity
 3. charitable lead trust
 4. life insurance policy or 401(k) retirement funds
 5. gift of appreciated assets (stocks, mutual funds and bonds)
- Gifts may be applied to the Society's general operating purposes or restricted to one of our research, family support or legislative programs.

CONTACT: terri@mpssociety.org or 919.806.0101



Jake Kreul was born in Hawaii and diagnosed with MPS IVA at age 6 months. He and his parents have been involved with researchers looking for treatments ever since. They traveled for two and a half years to Oakland every week for clinical trials of enzyme replacement therapy, and to Washington, DC, for an FDA advisory committee meeting to approve the treatments (Vimizim). Jake now receives weekly infusions in Hawaii.

Jake works with his father at his jewelry store in Kailua every Sunday, and started designing his own collection of jewelry using sterling silver and sea glass. Called the Draco Collection, it is named after one of Jake's favorite dragon characters in a book. For every piece sold, part of the money goes to the National MPS Society. After designing each piece, Jake's dad makes them by hand in his store, so every piece is unique.

To order, visit www.windwardjewelers.com or contact Doug Kreul at doug.kreul@yahoo.com.

2015 National MPS Society Runs

Sign-up, register or fundraise from your home!

The National MPS Society is hosting two national events this year, and we've made it easy for families to fundraise even if they cannot attend. Our goal is to raise \$100,000 that will benefit research, family support and many Society programs. Have fun, share your story, come run with us!

- Click the QR code from your phone or visit the website.
- Make a donation, build a fundraising team or Adopt a Runner Champion a Cure.*
- Share with family, friends and colleagues.
- Use social media with easy-to-use links found on the website.
- Help us make a difference—we can do this together.



Run the Night – 5K Run/Walk

Sept. 18, 2015

Salt Lake City, UT

<https://support.mpssocietygive.org/saltlakecity5k>

Race Director: Holly Thompson,
hethompson@gmail.com



Rare Run – Superhero 5K Run/Walk & Fundraiser

Oct. 17, 2015

Los Angeles, CA

<https://support.mpssocietygive.org/rarerunla5kfundraiser>

Race Director: Tami Slawson,
rarerunla@gmail.com



* Adopt a Runner, Champion a Cure at our National Run Events!

- Adopt a runner at one of the two National MPS Society walk/run events! They will run on behalf of your child. A picture of your child will be attached to the runner's T-shirt the day of the event. The runner will receive a packet with your child's picture, fun facts about your child and information about the National MPS Society.
- You participate in fundraising by collecting donations through one of the team pages above. Share on social media, with neighbors and friends.
- After the run, you will receive a picture of your adopted runner with your child's picture on their shirt. You also will receive a Champion Medal and a 5x7 photo.